

particular problem disclosed in our State is an excellent illustration of the basis for a 1929 quotation attributed to Sir Josiah Stamp:

The government (statisticians) are very keen on amassing statistics—they collect them, add them, raise them to the nth power, take the cube-root and prepare wonderful diagrams. But what you must never forget is that every one of these figures comes in the first instances from the . . . village watchman, who puts down what he damn pleases.

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The Nationalization of a Disease: a Paradigm?

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Synopsis.....

The early history of the Federal involvement in Hansen's Disease reflects the history of the Public Health Service itself. As a young and aggressive institution, the Public Health Service sought out contagious, infectious diseases that threatened the public health. National resources and national coordination were needed to fight the likes of malaria, hookworm, or smallpox. The customary attack would consist of a field study, determination of the etiology, the method of transmission, and, then, perhaps, preventive measures. An eradication campaign would follow.

Leprosy fit perfectly into the model—a disease of unknown etiology, an unknown method of transmission, thought to be highly contagious, and no known cure. The United States launched a major investigation in Hawaii, where the disease was prevalent and its victims conveniently segregated.

The investigation failed. The Public Health Service then turned toward segregation and isolation as a way to fulfill its public health role. A bureaucracy was established around the idea that victims of leprosy must be incarcerated for the good of the public.

The institutionalization of the Public Health Service and the philosophy upon which its treatment of leprosy was based proved difficult to change when researchers in the field made major scientific breakthroughs in the 1940s. The realization that the disease was only feebly contagious, activities of patient organizations, and pressure from the media and the Congress did not achieve as dramatic results as the sulfone drugs did. The Public Health Service moved, but slowly. What are the lessons in all of this?

IN MARCH 1916, THE CONGRESS of the United States had before it a proposal to nationalize a disease (*la*). Never before had the Federal Government moved so boldly in the name of public

health. That the disease was leprosy made such a move all the more dramatic.

Leprosy was largely misunderstood in 1916, shrouded in mystery, its victims suffering as much

from myths as from symptoms. Its origins were Biblical or before. In the Middle Ages, the Roman Catholic Church reportedly held a requiem mass for those afflicted, announcing their "death" and reducing them to a life of ostracism and begging. It was a disease so odious that in late 19th century America, responsibility for it fell by default to the Federal Government. No State or local government would willingly take responsibility.

This is a history of the national involvement with Hansen's Disease (HD), an illness described in the "Merck Manual" (2) as a "chronic, usually mildly contagious, infectious disease affecting principally the cooler parts of the body—especially skin, certain peripheral nerves, anterior parts of the eye, testis, and mucous membranes of the upper respiratory tract and mouth."

HD is one of the many maladies grouped under the historical appellation of leprosy. The terms, "leprosy" and "Hansen's Disease" are used throughout this paper but not synonymously. I use both for accuracy and emphasis. I hope the reader takes the distinction without offense.

In 1891, the Marine Hospital Service, after several decades of struggle, was taking over the public health functions of the defunct National Board of Health. Surgeon General Walter Wyman was anxious to expand the authority of the service. He planned to establish a medical laboratory as good as any in Europe and a Federal quarantine service with absolute control over State and local health services (3a). To a lesser degree, he also wanted to establish Federal control over public health.

To extend his leadership in public health, Wyman successfully encouraged the Congress in 1902 to change the name of the Marine Hospital Service to the Public Health and Marine Hospital Service to increase the efficiency of the service and make the Federal Government responsible for the improvement of sanitary conditions.

The newly enlarged service then launched campaigns to eradicate epidemics of hookworm, pellagra, malaria, urban bubonic plague, and yellow fever.

Leprosy was not ignored. In 1901, the Service sent a questionnaire to 2,819 counties in the United States; they reported 278 cases of leprosy, only 72 of which were isolated (3b). The report emphasized, however, that the count was grossly inaccurate because of the nature of the disease. Patients, their families, and friends concealed the affliction. This underreporting was confirmed by Dr. Gerhard A. Hansen, the Norwegian physician

who discovered the *Mycobacterium leprae* in 1873. He discovered 120 cases of the disease in Minnesota alone during a trip to this country for epidemiologic studies.

It was clear that a totally accurate count was impossible, but there were sufficient numbers for the Public Health and Marine Hospital Service to regard leprosy as major target for attack.

Full Scale Attack

In 1898, Dr. Wyman had sent Dr. D. A. Carmichael, with President William McKinley's approval, to Hawaii, where HD was a major health problem, to make a complete report. Since 1867, Hawaii's victims of HD had been segregated on the Kalaupapa Peninsula on the north side of the island of Molokai.

Six years later, President Theodore Roosevelt, prompted by the Hawaiian Board of Health, the Territorial Governor, and the Territorial Representative in the Congress, requested Federal funding of a hospital and laboratory in the Hawaiian Islands "to study the cause and cure of leprosy." At that time, there were 856 HD patients in the colony on Molokai.

The Congress responded in 1905 with \$150,000 for the construction of a hospital and its first year's maintenance. One square mile on Molokai had been set aside by the Hawaiian legislature for a research reservation.

Fulfilling Wyman's desire for the best research facilities, the U.S. Leprosy Investigation Station on Molokai became the most modern laboratory in existence. Its first director was Walter R. Brinckerhoff, a Harvard University professor who supervised its construction and outfitting with the best equipment available, down to flush toilets, ice machines, and Haviland china.

Brinckerhoff had problems, however, with the native Hawaiians, the Americans in the Hawaiian bureaucracy, and with his attitude toward HD which he regarded as a hated wartime enemy to be attacked and vanquished (4).

While the station was being laboriously constructed with material either floated ashore or brought in small boats to the isolated spot, Brinckerhoff conducted his studies at the Leprosy Receiving Station near Honolulu. He and his wife never took up residence in the home constructed for them on Molokai.

The station was finally opened on December 23, 1909, with Dr. George McCoy soon taking over as its director. It was rigidly segregated into three

separate compounds for staff residences, administrative offices and laboratories, and hospitalized patients. There was little traffic between the residence and administrative compounds and the hospital and no traffic between the hospital and other parts of the island.

Field studies at the station required 40 volunteers from the nearby Kalaupapa settlement. Only nine could be found. Eventually, they all left because of the rigorous treatment plans and the hospital isolation (5). On August 7, 1913, Dr. McCoy closed the station (6).

HD research continued in Hawaii, however. The Public Health Service (PHS) ran a laboratory and hospital for 100–150 patients from 1921 until the outbreak of World War II in 1941 (6). At the time the station was being built, the Public Health Service's Dr. Rupert Blue served as health advisor to the Territorial Governor and board of health (3c).

How the closing of the Hawaiian station retarded progress in the care and treatment of HD will never be known. The reasons for the failure of the station have been attributed to the refusal of the superstitious and hostile Kalaupapans to volunteer, the traditional resistance of native Hawaiians to the idea of segregating HD victims, and general bitterness against the Americans who had occupied the islands (4).

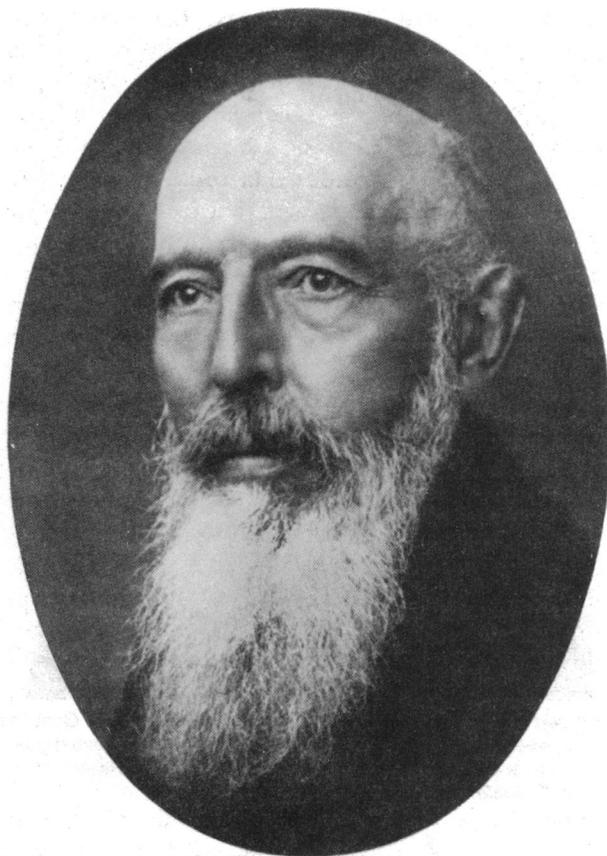
When Dr. McCoy and Dr. Blue later rose to higher positions in the Public Health Service, their HD priorities had shifted from the patient to the public and how it could be protected.

Care, Control, and Isolation

In 1912, Dr. Blue became Surgeon General of the Public Health and Marine Hospital Service and 8 months later hailed the enactment of a new law that, he said, "marks a new epoch in the history of the Federal Government, and . . . clearly recognizes the Public Health Service as the central health agency of the nation" (3d).

When Dr. Blue then appointed his colleague, Dr. McCoy, to the National Hygienic Laboratory (the research arm of PHS and forerunner of the National Institutes of Health), he set the stage for the Administration's favorable reception to proposals that included PHS involvement with HD.

At that time, only three places in the country had made any provisions for treating leprosy patients—California, Louisiana, and Massachusetts (1b). State laws regarding the disease were varied and mostly unenforced. And there were stories of persecution of HD victims.



Gerhard H. A. Hansen, MD, 1841–1912, a Norwegian physician who discovered the Mycobacterium leprae in 1873 and after whom the disease it causes was named.

A wealthy Chinese named Mock Sen was returning to the United States after completing his education abroad. It was discovered that he had contracted leprosy, and authorities locked him in a freight car and pushed it across the State line. Outraged citizens and railroad workers promptly pushed it back, and a 13-day tug-of-war ensued. When a young physician finally opened the box-car, Sen was found dead (1c).

John Early of Washington, DC, was also found to have leprosy. He was taken 4 miles out of the city and put under 24-hour armed guard. His wife and son lived in a house a few yards away. When winter came, Early was allowed to move into half the house, and the connecting doors were bricked over.

In December 1914 hearings before the House Committee on Interstate and Foreign Commerce, the American Medical Association (AMA) agreed with the Public Health Service that the Federal Government should segregate and control all lepers in the United States (7). Six months earlier, the AMA had declared that the burden was Federal



Rupert Blue, MD, health adviser to the Territorial Governor and board of health of Hawaii when the Molokai investigation station was being built and later Surgeon General of the Public Health and Marine Hospital Service.

because of the increase in the disease, inhumane treatment of patients, the possibility of contagion, and the economic onus on the States (8).

Surgeon General Blue felt that the best method of control was physical isolation in a remote area (7). An attempt had been made in 1905 to establish a "leper colony" in the Territory of New Mexico, but vigorous opposition of the Territorial legislature led to the defeat of the proposal in the U.S. House of Representatives despite passage in the Senate (1d).

Blue was urging the Congress to authorize the PHS to take over several smaller leprosaria on the theory that it would be more economical (7). When the Congress authorized a national leprosarium and appropriated \$250,000 for the purpose in 1917, Blue wanted to convert an existing hospital on Penikese Island in Buzzards Bay between the mainland of Massachusetts and Cape Cod. The citizens of New Bedford objected violently, as did those in the Pacific Northwest, in West Virginia, and in San Francisco when Blue's attention was turned to them (1e).

A three-member search committee headed by Dr. McCoy that Blue had commissioned to find a site fared no better. It ran into vigilantes off the Mississippi coast (1f) and similar resistance from a Florida island (3e).

The effort finally focused on the Louisiana Leper Home in Carville. The State would be glad to be relieved of the expense and the responsibility of caring for its 90 patients (1g). Both Louisiana Senator Joseph E. Ransdall and Dr. Isadore Dyer, founder of the home and dean of the Tulane University Medical School, approved of the federalization idea.

It was not until January 3, 1921—World War I having intervened—that the Federal Government paid \$35,000 and raised the American flag at Marine Hospital 66, taking it over lock, stock, and barrel.

Nationalization of a Disease

From that moment, the history of the Federal Government and HD is a history of Carville.

It had been established in 1896 after Dr. Dyer read a series of articles in the New Orleans Daily Picayune exposing the neglect and starvation of HD patients in a New Orleans pest house. He goaded the legislature into setting up a State Board of Control for a "leper home." His search for a suitable site ran into the same opposition the Federal one would 25 years later.

He finally found a deserted, run-down former plantation at Indian Camp, 75 miles northwest of New Orleans. He rented it on the pretext of raising ostriches there and then contracted with the Daughters of Charity of St. Vincent de Paul—a Roman Catholic order of nuns—to handle the kitchen, household, and nursing duties. When PHS took over the institution, the nuns became Federal employees and turned their salaries over to their mother house, which they still do today.

The philosophy at Carville from the beginning was that the patients should be physically restricted so as not to become a "menace" to the public. The 1917 Federal statute authorizing a national leprosarium echoed the same sentiments, authorizing the Surgeon General to establish a home to receive any person afflicted with leprosy for care detention, and treatment.

The 1922 implementing rules and regulations used such words as "parole," "apprehend," "hazard," "abscond," "detention," and "menace."

Soon after the Federal Government took over the Carville facility, patients began to arrive from all over the country. Leprosaria in Massachusetts and California were closed with a sigh of relief, and the patients transferred to Carville. The PHS even paid for transportation. Soon there were 180 patients at the Louisiana facility.

In 1923, the Congress appropriated \$645,000 for expansion and modernization to accommodate 425 patients. Twelve wooden cottages for patients, connected by screened walks, an infirmary, a surgical suite, and new laboratory equipment were provided.

The first Federal medical officer in charge of Carville was Dr. Oswald Denny, a quarantine officer and well-known leprologist who had been stationed in the Philippines. His first act was to raise the American flag and the Yellow Jack quarantine flag over the hospital, which, more or less, set the tone of the environment.

In the May 14, 1926, issue of *Public Health Reports* (9), Denny summed up his feelings on leprosy:

“To contract leprosy is not a crime. It is, in most cases, unavoidable. Once a leper is in detention, however, it is a crime against society for him to abscond and subject his fellow human beings to the risk of contracting a malady that is practically incurable. To restrain such an individual is for the public good. This the law does with justice.”

The quarantine atmosphere remained largely the same for the next 20 years, through new directors and several congressional appropriations to enlarge and improve the facilities at Carville.

In July 1940, Dr. Guy Faget became director at Carville. Having served at the PHS tuberculosis hospital in Fort Stanton, NM, Dr. Faget attempted to transfer at least 10 Carville patients there to study the effect of climate on HD (*Ih*). Patients at both Carville and Fort Stanton opposed the move. Each group, ironically, was a victim of prejudice about the other's disease. The PHS position was that the theory of a drier climate at higher elevation being beneficial to HD sufferers had not been proven (*Ij*). As a result, no climate studies were ever conducted.

His second experiment was more successful. Aware of the use of sulfonamides in the treatment of certain bacterial infections and of their effectiveness against tuberculosis, Dr. Faget thought sulfanilamide might work against some of leprosy's secondary infections. He chose nine Carville volunteers and administered several courses of the drug to them. Nothing happened for 6 months, then their skin ulcers began to clear up. The first paper on this development was published by Dr. Faget in the December 11, 1942, issue of *Public Health Reports* (10). Later, promin, a related drug of the sulfone series, was even more effective (*Ij*). By 1946, a total of 37



Guy H. Faget, MD, director of the National Hansen's Disease Center at Carville, LA, 1940-47, who achieved success in treating the disease with drugs of the sulfone series.

patients—twice as many as ever before—were discharged as arrested cases.

Liberation

Late in 1945, Carville patients formed a United Patients Committee for Social Improvement and Rehabilitation to force institutional changes that reflected medical advances. The committee proposed a 15-point program that called for:

Voluntary institutionalization; abolition of compulsory segregation and the common carrier ban against patients using public transportation; creation of early diagnosis and treatment clinics in other parts of the country; a study of the effects of climate; expanded research at the hospital; a plastic surgeon at Carville; financial aid for patients' dependents; occupational therapy; quarters for married couples, families, and visitors; recognition of Hansen's Disease as the official name for leprosy; and permanentization of an advisory committee (*Ij*).

The American Legion, concerned because so many Carville patients were veterans, also urged the advisory committee to study the care, treatment, and rehabilitation of patients. The committee was formed in 1946 with Dr. McCoy as one of its members.

It was really Gertrude Hornbostel, however, who advanced the cause of HD patients. The wife

of a retired army major in San Francisco, Mrs. Hornbostel was diagnosed as having HD in 1946. Her husband promptly announced to the press that he would accompany his wife to Carville and would stay there with her (1k).

The case immediately became a national sensation, and six months after the Hornbostels entered Carville, the new advisory committee drew up recommendations for patient leaves of absence, free transportation on leave, diagnostic and treatment centers in States with HD victims, financial aid for patients' dependents, recreational and vocational programs, quarters for married couples, social worker contact with patients' families, and a national education campaign on HD (1l).

Some of the recommendations were adopted immediately, others took several years, but the breakthrough had been made. PHS rules and regulations were rewritten in 1975.

In the meantime, the Carville facility itself changed. Barbed wire fences came down, and patients were given medical discharges instead of PHS leper identification. And not all discharged patients were cured. Those from homes without children who could afford care and had a physician willing to report monthly to Carville were released to outpatient care (1m). By 1950, the PHS had removed leprosy from its list of quarantinable diseases.

Slowly, other Carville inmates were absorbed into the regular PHS hospital system. By 1980, HD patients could receive treatment, as outpatients or otherwise, at PHS hospitals in various cities.

Then in 1981, at the direction of the Congress, all PHS hospitals but the one at Carville were closed. (In March 1986, the name of the National Hansen's Disease Center was changed to the Gillis W. Long Hansen's Disease Center to honor the late Louisiana Congressman.)

Conclusion

The January 31, 1983, issue of Newsweek Magazine claimed that an increasing number of people in the United States are afflicted with HD (12). Joseph and coworkers at Carville said recently in *Public Health Reports*, however, the number of HD cases reported annually in the United States reached a peak of 396 in 1981, with most new cases being among immigrants (13). Most victims can now be treated in their home communities with prolonged hospitalization no longer necessary, the authors said.

Joseph and colleagues concluded their study of Carville records over a 50-year period with this observation (13):

"Possibly the most interesting finding was the trend of increasing age at diagnosis over the 50-year period studied, with acceleration of this trend in the past two decades. This trend appears to be statistically significant and would predict the ultimate disappearance of Hansen's Disease in native-born citizens (of the United States) if the present trend continues. The noted trend is consistent with previous observations that Hansen's Disease tends to disappear in countries with a high standard of living."

While HD is still with us as a "national" disease, there is another generation of policy decisions to be made—including whether to denationalize it.

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